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ABSTRACT

A number of problems faced by the custodians of large collections of data which are potentially useful for research in the behavioral sciences, are addressed in this presentation. These problems relate to the rights of individuals who provide research data, to questions of "informed consent", and to the circumstances under which the public interest takes precedence over obligations to individuals. (Author/MV)

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Conflict of Responsibility: The Databanker's Dilemma

It is the thesis of this paper, as suggested by its title, that the custodians of large collections of data having potential value for research in human behavior are subject to demands and prohibitions which, on occasion, place them in true dilemmas. In responding to the demands, they are likely to find themselves in violation of a prohibition: in respecting a prohibition, they may be accused of failing to respond to a need. One doesn't wish to make too much of the matter--to appear to be tooting the horns of his own dilemma, so to speak--but, many of us in this room have felt the divergent demands that are levelled against the collector and holder of data, demands that can be particularly troublesome when it becomes a question of performing secondary analyses for purposes for which the data were not originally collected and about which the suppliers of the data have no knowledge.

Ultimately, it seems to me, the dilemma is rooted in certain of the elements which make up the social context within which behavioral research is conducted. One such element is the increasing dependence of society on behavioral research for purposes of decision-making and policy formulation. As the components of society become more closely articulated and as it becomes increasingly possible for local disturbances to send seismic shocks throughout the whole structure, it becomes more important to understand the forces that influence the behavior of individuals, groups, and institutions, the extent to which such behavior is predictable, and the circumstances under which various kinds of behavior are likely to be elicited.

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At least since 1950 there has been explicit public recognition of the willingness of decision-makers at the highest levels to profit from the help that behavioral scientists can provide. A landmark in this developing awareness was the judicial opinion issued in 1954 in connection with Brown vs. Board of Education where the Supreme Court documented its reliance on the studies and conclusions of social scientists relative to the difficulty of insuring equality of education when it was conducted in segregated circumstances. Twenty years later it is accepted as a matter of course that, in administering existing legislation or in recommending new legislation, all branches of government regularly assemble the relevant results of existing research or, with increasing frequency, are prepared to sponsor research designed to answer the specific question at hand.

To behavioral scientists, who may see credit accruing for themselves with the powers that be, the developments just described are most gratifying. Looked at from the other side, however, the coin does not appear quite so negotiable. There is an undeniable current of skepticism about the value of behavioral research, taken in the aggregate, which runs deep in the popular mind but is detectable too in more intellectual circles. From within the ranks of the profession voices are occasionally heard deploring the production of voluminous research results which, for the most part, are decently interred in the files of foundations and governmental agencies or sink without a trace into the journalistic morass. Most of us have shared such doubts at one time or another. Senator Proximire made the point in much stagier fashion through his Golden Fleece awards which were offered periodically to the recipients of public research funds whose projects were, in his eyes, distinguished by the triviality of their conception and the irrelevance of their findings.

Out of the reassertion of individual rights which so preoccupied the country during the 1960's, grew a number of attitudes which have survived into the '70's and which have far-reaching implications for behavioral research. The consumer became an object of general solicitude and, as part of the effort to enhance consumer-power vis-à-vis the entrenched might of the corporations, there occurred a strong assertion of the proprietary rights of individuals in data pertaining to them. Information is power and it should not be turned over lightly to organizations who may use it to exploit the supplier. Even in instances where exploitation is not the issue, the individual has the right to be left alone and to reveal himself only at times and under circumstances of his own choosing.

Feeding into this attitude is a tendency toward the politicizing of behavioral research. Research, it has been discovered, can be used to gain benefits for groups hitherto deprived or to protect the vested interests of groups already in power--frequently without the necessity of departing from the letter of principles governing scientific investigation. It has become a matter of concern to many individuals to know the probable consequences of any research to which they may lend themselves--otherwise they may find themselves collaborating in their own exploitation.

Finally, and with no pretense to having been exhaustive, one might point to the reluctance of the public to put its trust in codes of conduct promulgated by professions, in statements of policy purporting to govern the conduct of institutions, or in the good sense, good judgment, and ethical stamina of individuals. Increasingly, conflicts at the local level must be resolved by lawmakers and the writers of regulations so that, for example, the

inability of parents to extract information about their children from the local school system must ultimately be established by an act of the federal legislature. The result is that behavioral research and the creation and maintenance of the data-bases on which such research depends are conducted in a growing welter of federal and state legislation. In saying this, one does not wish to deny the need for high-level concern in these matters nor to denigrate well-intentioned remedial efforts now under way. But the field is new, experience is wanting, and first efforts are often clumsy.

What do these ruminations have to do with data-banks, particularly those that are relevant to educational research? Before meeting that question head-on, there is a distinction worth making. There are at least two classes of data-banks, if one is thinking of the useability of the data they contain for educational research. Some, such as those established in connection with Project Talent or the National Assessment of Educational Progress, were created for specific research purposes which are known to the public and, more particularly, to those supplying the data. So long as the research based on the data stays within the preestablished limits, questions of propriety about the uses to which the data are put are not likely to be raised.

Other data-banks may be established primarily for administrative purposes--incidental to providing a service or to facilitating a business activity--with no plans for specific research application. This is likely to be true of files collected by governmental agencies and educational institutions and of files accumulated in connection

with large testing programs such as those at ACT or ETS. Though collected for what are primarily non-research purposes, these files can, on occasion, become very attractive to researchers in human behavior and in education. That interest can, in turn, give rise to questions as to the extent to which such files should be made to serve purposes not specifically articulated at the time of collection. Taken together, these questions point up one of the issues which face this symposium--namely, the propriety of secondary analyses of existing data sets.

To come to the point, then, what I have been trying to say is this. The attitudes of society, as represented by legislators, staffs of government agencies, consumer advocates, and the press, toward data-banks offering the potentiality for behavioral and educational research are distinctly schizoid. On one hand, they embrace the recognition that, as social institutions become more complex, more data, appropriately analyzed, are needed to support the functions of governing and managing. On the other hand, these attitudes contain a large element of resentment directed at organizations that amass and maintain large collections of data pertaining to individuals. This resentment is based largely on fear that individuals may be exposed to harm through careless or unwise management of data and on the belief that control of data confers a large measure of power which is beyond supervision by agencies serving the public interest.

As a result of these attitudes, data-bankers are placed in a double bind: they are charged with a responsibility, imposed by

public expectation and by standards of professional conduct, to exploit the data in the public interest; on the other hand, they are compelled to use the data in circumstances which are significantly restricted by consideration of the interests of the individuals to whom the data pertain.

In many institutions--notably those which aspire to HEW funding for research involving human subjects--the issues raised by these considerations come to focus in institutional review boards established under HEW regulations. At ETS, where the functions of the review board have been broadened to include monitoring all ETS research, the board operates in light not of one but of three sets of federal regulations: the HEW regulations for the protection of human subjects in research; the Privacy Act of 1974; and the Family Education Rights and Privacy Act. In doing so, it concerns itself in the main with the following issues: the potential contribution of the proposed research to the public interest, the degree of risk to which subjects are exposed, maintenance of confidentiality, procedures for obtaining informed consent, and release of data for research purposes. For the balance of the paper, I will concentrate on the latter two considerations--namely, procedures for obtaining informed consent, and release of data for research purposes.

The HEW guidelines, which govern the formation and operation of institutional review boards, were originally a response to the need for stricter control of the rights of subjects in bio-medical research where subjects were quite literally "at risk." While conceptualization of the guidelines has been broadened to make them applicable also to behavioral research, the bio-medical slant is still apparent. Thus, they are concerned more with requiring candor

regarding the nature of the experimental treatment and the extent of entailed risk than they are with the right of subjects to control data after they have been collected. The Privacy Act of 1974 and the Family Educational Records and Privacy Act, on the other hand, are concerned exclusively with the use and management of data after collection. The concept of "informed consent" applies to subjects' assent to the use of data after it is in hand rather than to the subjects' willingness to submit to experimental treatment.

For the vast bulk of behavioral research, the obtaining of informed consent as related to treatment poses few problems. The experimental procedures are generally benign and the subjects are not "at risk" in any gross sense. There may be a small class of experiments falling between physiology and psychology where this is not true. Also, there have been some experiments involving deception which, as in the case of the Milgrim studies of obedience, may on occasion become quite heroic and where the risks of psychological harm may be great. But such cases are extreme and are not profitable to linger over here.

However, for purposes of this discussion one point does need to be made. Often, a part of the bargain in obtaining informed consent is an undertaking on the part of the researcher to preserve the confidentiality of data collected during the study. The terms in which this undertaking is put can be important. Possible extensions of the uses of the data beyond the immediate purposes of the project in hand cannot always be foreseen. If an agreement covering confidentiality is spelled out too narrowly, later desirable research may be foreclosed. It is better to restrict agreement to a promise

that identifiable data will never appear in a published report and that they will be used only in the immediate project, or in related research carried out under comparable conditions of confidentiality. Other unlikely contingencies that might be mentioned are auditing by the funding agency or response to a valid subpoena.

Coming now to the issue of releasing individually identifiable data without the informed consent of the individuals concerned, it is this issue which puts the conflict underlying this symposium in its most acute and dramatic form. There are at least four reasons why such release might be sought: 1) for additional analyses which are essentially extensions of those performed in the original study; 2) for reanalysis to provide an independent check on the validity of the original analysis; 3) for purposes of auditing data collection procedures to ensure that the data in hand are accurate; 4) for use in a research project of different purpose and design requiring the incorporation of new data. For the first three of these purposes--extended analysis, reanalysis, and audit--it could be argued with some plausibility that these are so closely connected with the original project as to be accommodated by the original undertaking regarding confidentiality. Indeed, for the first two, it is hard to imagine circumstances under which the data would have to be released in identifiable form.

It is a request for release of data for the fourth of the purposes cited above that can place the data-banker on the horns of an excruciating dilemma. To embrace the dilemma in its full, thorny splendor, consider the case of the researcher who has collected data with informed consent from the individuals concerned to use them for specified research purposes and who is asked by another research to release them in identifiable form for use in research

which was not contemplated at the time of initial collection and about which the subjects are consequently ignorant. In view of the unequivocal undertaking with the subjects, presumption must inevitably favor refusal. But that seldom finishes the matter. Data-bankers, in the persons of researchers, institutional review boards, and the organizations they represent, feel the tug of other considerations, which have figured prominently in this afternoon's discussion--namely, the need for ready access to data if the principle of freedom of scientific inquiry is to be sustained and, second, the possible involvement of the public interest which, in some circumstances, may be preemptive.

Of these two possible justifications for releasing data, the second, the public interest, would no doubt gain the widest acceptance--indeed, freedom of scientific inquiry achieves legitimacy in part because it contributes to the public interest. The concept is, however, excessively vague. HEW, in its regulations governing internal review boards uses the term in certain crucial contexts but makes no effort to define it. The literature of philosophy and political science, insofar as I have dipped into it, tends to treat the public interest as one of those mythic generalizations which are necessary in certain types of social discourse but which defy precise definition. In any case, the literature provides little by way of practical guidance. The institutional review boards are left, then, pretty much to their own perceptions, biases, and instincts.

Difficult though they may be, decisions of this character occasionally have to be made by internal review boards and others. Fortunately, the frequency of situations requiring such decisions is low, but, when they arise, they evoke a disproportionate amount

of agonizing and they induce powerful feelings of doubt and insecurity in those who have to make them. The internal review board at ETS has tried to introduce a measure of order into its procedures for dealing with these matters by formulating for its own guidance the following set of criteria which, as you will note, deal with the issue of defining the public interest by begging the question.

a) The Committee will make a judgment as to whether the outcome of the proposed research is likely to be of substantial scientific and social value and whether the potential benefits to society outweigh the likelihood of injury to the subjects.

b) The Committee will satisfy itself that no feasible procedure could be worked out for matching data without the use of identifying information.

c) The Committee will ascertain from those responsible for maintaining the data that no special restrictions exist regarding its release, e.g., in the case of data collected under contract with a governmental agency which is subject to the Privacy Act of 1974.

d) The recipient organization will be required to demonstrate that it has in force a policy for safeguarding confidentiality and effective procedures for carrying it out.

e) The recipient organization will undertake to restrict the number of persons having access to the data--certainly to a group no greater than the project staff and preferably to a named subgroup within it.

f) The recipient organization will agree to keep a separate linking file for purposes of matching data.

g) The recipient organization must agree to destroy the linking file at the earliest possible moment consistent with completion of the project.

Prospects for the future in the management of data-banks are likely to be heavily influenced by the work of the Privacy Protection Study Commission, which was established pursuant to provisions of the Privacy Act of 1974 and which is expected to report to the President, the House, and the Senate in June 1977. It has held hearings on educational data systems and on the uses of data in research, as well as in numerous other fields in which data are systematically accumulated. Its recommendations for legislation governing the accumulation and permissible uses of data will unquestionably affect profoundly the conduct of research in human behavior and in education.

The Commission has already produced in draft form for purposes of discussion a set of policy statements regarding the management of data in research. From the point of view of the researcher, it is, by and large, a remarkably liberal document. Most relevant to the concerns which motivate the present discussion is a provision for releasing identifiable data for research purposes. The language of the draft is as follows:

> Disclosure in individually identifiable form of any information or record collected or maintained for a research or statistical purpose should be allowed

for another research or statistical purpose without the authorization of the individual to whom such information or record pertains only when:

- prohibition of use or redisclosure for all other purposes is made a condition of the disclosure;
- disclosure in individually identifiable form is necessary to accomplish the research or statistical purpose for which disclosure is to be made; and
- the importance of the research or statistical activity for which the disclosure is to be made is such as to warrant the additional risk to the individual.

Insofar as the language of this provision finds legislative expression at some time in the future, it will go far toward reducing the tensions which have been the concern of this paper.

It is my impression, then, that the existence of the Privacy Commission augurs well for the interests of researchers. It is doing an impressive job of compiling facts and of exploring relevant points of view on the issues involved. Its report is likely to strike a judicious balance among competing social concerns. The processes of collecting and using data for behavioral and educational research are likely to come under a considerable degree of restriction, as indeed they should. However, such restrictions as are imposed will be carefully thought through and will be rationally based. Indeed, the report is likely to reflect a fairly liberal attitude toward research and the social

contribution it is capable of making and may well lend a dimension of welcome legitimacy to practices such as some of those we have been discussing, which we have hitherto pursued in a state of considerable uncertainty, some trepidation, and perhaps a hint of guilt.

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